

ORIGINAL ARTICLE

# Active Rehabilitation—a community peer-based approach for persons with spinal cord injury: international utilisation of key elements

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**Introduction:** Active Rehabilitation (AR) is a community peer-based approach that started in Sweden in 1976. As a key component of the approach, AR training camps provide intensive, goal-oriented, intentional, group-based, customised training and peer-support opportunities in a community environment for individuals with spinal cord injury.

**Study design:** Prospective cross-sectional study.

**Objectives:** To describe the profile of the organisations that use components of the AR approach, and to explore the characteristics and the international variations of the approach.

**Setting:** Twenty-two organisations from 21 countries from Europe, Asia and Africa reported using components of the AR approach during the past 10 years.

**Methods:** An electronic survey was developed and distributed through a personalised email. Sampling involved a prospective identification of organisations that met the inclusion criteria and snowball strategies.

**Results:** While there were many collaborating links between the organisations, RG Active Rehabilitation from Sweden and Motivation Charitable Trust from the United Kingdom were identified as key supporting organisations. The 10 key elements of the AR approach were found to be used uniformly across the participating organisations. Small variations were associated with variations in country income and key supporting organisation.

**Conclusions:** This is the first study to describe the key elements and international variations of the AR approach. This will provide the basis for further studies exploring the effectiveness of the approach, it will likely facilitate international collaboration on research and operational aspects and it could potentially support higher integration in the health-care system and long-term funding of these programmes.

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## INTRODUCTION

There is compelling evidence that, no matter how specialised the acute care and in-patient rehabilitation for persons with spinal cord injury (SCI), newly injured individuals feel unprepared physically and psychologically to transition to home.<sup>1–6</sup> Community-dwelling individuals with SCI report a number of unmet needs, especially related to psychological health, lifestyle, community functioning, self-efficacy and information.<sup>5–8</sup> Unmet needs are correlated with lower outcomes, including social isolation<sup>5</sup> and development of potentially fatal medical complications,<sup>7</sup> which markedly increase the impact of disability on the individual, their families, communities and the state.<sup>9</sup> Except from the inherent complexity of SCI, unmet needs have been attributed to a number of factors such as limited access to care and services,<sup>7,10</sup> inaccessible and demanding community environment,<sup>2</sup> and in some settings to considerable reductions in length of stay of in-patient care and rehabilitation.<sup>11</sup>

In that context, community programmes have gained an increasingly important role in the subacute and long-term management of SCI.<sup>12</sup> Although there are often many community services supporting the medical and care needs after discharge,<sup>4,13,14</sup> there are limited available options of community programmes addressing the long-term physical, emotional, independent living and lifestyle needs of individuals with SCI.<sup>3,5,7,10,14,15</sup>

The concept of active rehabilitation was recently described by Hultling and Montero<sup>16</sup> as a number of important aspects that can make in-patient rehabilitation more meaningful and relevant to newly injured individuals with SCI. We hereby refer to Active Rehabilitation (AR) as a specific community-based approach that started in Sweden in 1976. It is a grassroots transfer of practical life and social skills from experienced and active individuals with SCI (peer mentors) to newly injured individuals or others who need it. This is achieved by sharing knowledge and skills as well as by developing a progressive attitude through inspiration and motivation. The main focus of this

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consumer-driven intervention is to support individuals with SCI to improve their independent living skills and self-esteem, and subsequently to reach their full potential at an activity and participation level. The AR approach was initially designed to include: (1) first contact programmes; (2) training camps; (3) follow-up services and (4) community education programmes (Box 1). The training camps, in particular, provide intensive, goal-oriented, group-based, individualised training opportunities in a community-like, non-hospital environment. Box 2 presents the 10 key elements of the training camps.

Over the past 40 years, components of the AR approach have been adopted by organisations in more than 20 countries in Europe, Asia and Africa. Most of these not-for-profit organisations have evolved

### Box 1 Main components of AR approach

*First contact activities:* This involves an early contact of the newly injured person with a peer mentor during the acute stage or during rehabilitation. AR organisations usually have designated contact persons (e.g. nurses, therapists, doctors) in acute facilities and rehabilitation centres. At an appropriate time-point, the contact person offers the opportunity to the newly injured individual and their family to meet with a peer mentor from the AR organisation. Sometimes the meeting is one-to-one and other times there is a group information session. The peer mentor and the newly injured person are usually matched based on characteristics such as gender, age and level of injury.

*Training camps:* A training camp is the most common activity of AR organisations. Some camps target newly injured individuals, while other camps target children and adolescents, women and individuals who have been living with their disability for many years. Typically, AR training camps provide intensive, goal-oriented, intentional, group-based, customised training and peer-support opportunities for individuals with a SCI in a community environment.

There are 10 key elements of AR training camps: (1) peer mentors; (2) non-disabled assistants; (3) Activities of Daily Living (ADL) and wheelchair skills training; (4) use of sports and recreational activities; (5) education; (6) training environment; (7) admission criteria; (8) setting goals, initial and final assessment; (9) training of peer mentors; and (10) duration of the AR camps. The structure and content of the camp may vary between countries depending on culture and climate. Typically, camps have around 2–3 practical sessions during the day lasting between 1 and 3 h each. The practical sessions may be designated to training wheelchair skills, transfers, strength or to practicing a specific adapted sport. There are also evening sessions, which involve either a discussion on a designated topic, watching a selected movie or informal discussions.

*Follow-up activities:* Often AR organisations maintain contact with former participants to provide on-going support. This is accomplished in a number of ways, such as short camps and targeted thematic activities, face-to-face individual or group-based meetings, or contact through phone and digital methods (e.g. email, social media).

*Community awareness and educational activities:* This is aimed at developing community awareness on issues related to physical disability. This may include showcasing skills that somebody can develop through the AR activities, getting community members to try out a wheelchair and adapted activities or to promote injury prevention. These activities may be oriented to the general public (e.g. in festivals or other public events), or they may target a specific population group (e.g. children through school visits). Furthermore, organisations may provide educational sessions to health professionals and university students in relation to the lived experience of physical disability, as well as training on wheelchair skills and ADL.

through international collaboration. Despite having been widely used for so long across the world, the key elements of the approach and the characteristics of the organisations using it have not been researched in the international scientific literature. Paradoxically, despite a plethora of positive anecdotal evidence, the effectiveness of the approach has not been systematically explored.

As with other types of community health-care services,<sup>17</sup> we have assumed that lack of description and scientific evidence has had negative implications for AR organisations in relation to funding, integration in the health-care system and access to consumers. The aims of this study were to explore and describe:

1. The profile of the organisations that use components of the AR approach.
2. The international variations in the type and focus of the AR activities.
3. The characteristics of the participants and the personnel involved in these activities.

## MATERIALS AND METHODS

### Study design

This was a cross-sectional descriptive study that used a purposely developed electronic survey that was distributed online among organisations using AR approach. The project was approved by the Central Queensland University Human Research Ethics Committee, approval number H16/03-061.

### Procedure

All organisations and entities (from this point referred to as organisations) that had offered, directly or indirectly, AR training camps during the past 10 years were invited to participate in the study. Most of the potential organisations for inclusion in this study were identified by members of the research team. Some others were identified through purposive snowballing methods, whereby the identified organisations were asked to recommend others who met the inclusion criteria. Information sent to the organisations made clear that participation in the study was voluntary, that they were free to disclose only information that they found appropriate, and also that they had the right to withdraw from the study at any time. Submission of a completed survey implied consent to participate in the study.

Data collection took place from May until July 2016. An email with information about the study and the link to the online survey was sent to a key contact person from each organisation. This person was invited to complete the survey and was encouraged to forward the communication to other organisations that potentially fulfilled the inclusion criteria. The same researcher who made initial contact sent up to three reminders. In cases where more than one responses were received, further contact with the organisation was made to identify the most accurate response.

Before publicising any dissemination material, key contact persons from major participating organisations were provided with a written report describing the main study findings. Time was allowed for the contact persons to provide feedback and raise any concerns. If the contact persons did not raise any issues within the given period of time, the authors assumed that the report was approved.

### Survey

The authors of this study—all with large experience in the AR approach—developed the electronic survey in Survey Monkey. The questions were piloted with two organisations and minor changes were made based on their recommendations.

The survey included 30 questions that were organised into four sections. The first section collected information about the characteristics of the organisation, the funding sources and the number of employees. The second section collected information about the type of activities that had been organised over the past 10 years. The third section asked the organisations to indicate which of the identified 10 key elements of the training camps were incorporated in their programmes. The fourth section explored aspects related to the individuals

## Box 2 Ten key elements of AR training camps

### 1. Peer mentors

Designated experienced individuals with SCI are involved in the training of participants. Often they undergo regular training related to their role, knowledge and skills they need. Because they are a real-life example of what participants could achieve, they are often referred to as *role models*.

### 2. Non-disabled assistants (also known as support group)

Non-disabled persons are either involved with organisational aspects, training aspects or with the provision of personal assistance to participants. They often have a health professional education background (i.e. studying or working as physiotherapists, occupational therapists, nurses). They may be working as personal assistants/carers, or have a completely different background. The participants are discouraged from bringing their carers or family members to the camps, but sometimes this is unavoidable owing to the lack of availability of other non-disabled assistants, or because the family member or the carer needs to be trained.

Typically, members of the support group are not assigned to specific camp participants but rather they work as a group and rotate. In that way, they are exposed to participants with different needs and types of injuries, and at the same time they rely on the participant to provide the right information about the type of assistance needed. Members of the support group usually undergo training that is provided by the AR organisation before the training camps.

### 3. ADL and wheelchair skills training

Training of ADL is incorporated in the daily schedule as needed, with the help and under the guidance of peer mentors and a support group. For example, training of toilet transfers, showering and dressing occur at the natural time and environment. All sessions have some degree of flexibility that allows participants to individualise training and interact with others. Wheelchair skills training typically involves custom-based ramps and stairs, and progresses to the natural environment including the city centre. The purpose of this is dual: participants get to use their new skills in the natural environment, and the public develops awareness of active wheelchair users.

### 4. Sports and therapeutic recreation activities

AR camps include a variety of sports and recreational activities with the aim to improve function, level of independence and also introduce activities that the participants can then practice on a regular basis. Most camps offer weight lifting and general fitness training, table tennis, swimming and archery. However, some of these sports may be excluded (e.g. swimming), and other sports may be included (e.g. basketball, self-defence) according to locally available equipment and facilities. Availability of the activity in the community will influence the decision whether to include the activity or not.

### 5. Education

Education sessions during the camp are intended to help participants acquire or maintain knowledge that would allow them to optimally manage their condition. These sessions may include: (a) introduction to SCI, (b) wheelchair adjustments, (c) prevention of pressure sores, (d) prevention of urinary tract infections, (e) bowel management and (f) sexuality and fertility. The topics are chosen based on participants' needs, as well as on contextual factors.

### 6. Training environment

AR camps are organised in wheelchair friendly facilities (e.g. buildings with wheelchair access, accessible bathrooms etc.). In middle- and high-income countries, participants usually share rooms with their peer mentors. These facilities are either in hotels, schools, sports or recreational complexes. This creates a real-life learning environment that is very different from that of a hospital, sports or recreational activity setting. In some low-income countries, where such facilities are not readily available, AR camps take place in hospital environments. In such cases, participants arrange their own accommodation and attend on a daily basis.

### 7. Admission criteria

AR camps are short, intensive and demanding experiences. For the participants to be able to benefit from such experiences, they must be free of severe complications, such as pressure sores. Some organisations have further admission criteria, such as for the individual to be able to roll the wheelchair on a flat surface. Admission criteria will ensure that the camp is suitable for the participants and minimise the level of risk, given that in most of the camps there is not necessarily a nurse or medical officer present.

### 8. Setting goals, initial and final assessment

At the start of the camp, participants are asked to provide background information for themselves and to complete a self-assessment related to their level of independence in ADL, their general condition and their training goals. This information will be used to customise the intervention to their functional level and needs. Self-assessment occurring at the end of the camp will determine any changes in relation to outcomes. During the camp, regular staff meetings are organised to discuss assessment findings as well as to discuss the progress of participants, daily routines and logistics. These meetings are an important part of the AR intervention as they minimise the risk of making mistakes, while regularly adjusting the level of support that is provided to participants. Participants at AR camp are also assessed at the end of the camp with regard to their goal attainment and satisfaction.

### 9. Training of peer mentors

Former participants of AR camps can become peer mentors. This transition is completed through participation in special train-the-trainers camps, as well as having the ability to deliver practical and/or theoretical sessions. New and experienced peer mentors attend training workshop that include a variety of topics, such as anatomy, prevention of complications, health promotion, management of impairments, role of the leader and organisational aspects.

### 10. Duration of the AR camps

Duration of the camps usually varies from 5 to 10 days depending on available funding and personnel. This timeframe gives enough time for participants to familiarise themselves with the programme, to train and to interact with peer mentors and other participants.

involved with running the activities and any important connections of the organisation with other organisations.

### Data analysis

Descriptive data were presented as *N*, mean and standard deviation (s.d.). Countries were classified according to their gross domestic product (GDP) and region based on data from the World Bank databank.<sup>18</sup> All statistical analyses were performed with the Statistical Package for Social Sciences (SPSS) software (v. 22.0; SPSS, Chicago, IL, USA).

## RESULTS

### Participating organisations that use components of the AR approach

Twenty-three organisations from 21 countries (three from the United Kingdom) completed the survey. One organisation was excluded from analysis because it did not meet the inclusion criteria. In addition, another organisation was invited to participate but did not respond. Overall, 22 organisations were included in the study: 11 from Europe,

**Table 1 Demographic information about study participant: 22 organisations from 21 countries**

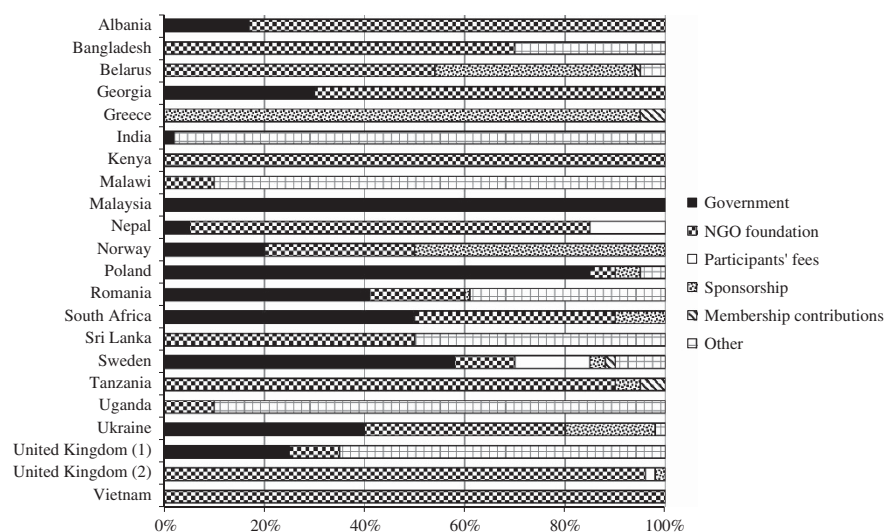
Organisations that offer active rehabilitation training camps					
No.	Country	Country region	Country income	Name of organisation	Type of organisation
1	Albania	Europe	Upper Mid	Albanian Disability Rights Foundation <sup>a</sup>	NGO
2	Bangladesh	Asia	Lower Mid	Vitality <sup>b</sup>	NGO
3	Belarus	Europe	Upper Mid	Public association 'Republican Association of Wheelchair Users' <sup>c</sup>	NGO
4	Georgia	Europe	Upper Mid	Coalition for Independent Living <sup>b</sup>	NGO
5	Greece	Europe	High	Alli Opsi <sup>c</sup>	NGO
6	India	Asia	Lower Mid	Indian Spinal Injuries Centre <sup>b</sup>	NGO
7	Kenya	Africa	Lower Mid	Motivation Kenya <sup>a</sup>	OTH
8	Malawi	Africa	Low	Motivation Malawi <sup>a</sup>	NGO
9	Malaysia	Asia	Upper Mid	University of Malaya Medical Centre <sup>b</sup>	GOV
10	Nepal	Asia	Low	Spinal Injury Rehabilitation Centre <sup>a</sup>	NGO
11	Norway	Europe	High	Sunnaas Foundation & Sunnaas Rehabilitation Hospital <sup>c</sup>	FOU
12	Poland	Europe	High	Foundation for Active Rehabilitation <sup>c</sup>	FOU
13	Romania	Europe	Upper Mid	Motivation Romania Foundation <sup>a</sup>	NGO
14	South Africa	Africa	Upper Mid	Afrique Rehabilitation and Research Consultants <sup>b</sup>	OTH
15	Sri Lanka	Asia	Lower Mid	Motivation Sri Lanka <sup>a</sup>	NGO
16	Sweden	Europe	High	RG Active Rehabilitation (key supporting organisation)	NGO
17	Tanzania	Africa	Low	Kilimanjaro Association of the Spinally Injured <sup>a</sup>	NGO
18	Uganda	Africa	Low	Motivation Uganda <sup>a</sup>	NGO
19	Ukraine	Europe	Lower Mid	Ukrainian Civil Organization of People with Disabilities 'Group of Active Rehabilitation' <sup>c</sup>	NGO
20	United Kingdom (1)	Europe	High	Motivation Charitable Trust (key supporting organisation)	NGO
21	United Kingdom (2)	Europe	High	Back Up <sup>b</sup>	NGO
22	Vietnam	Asia	Lower Mid	Handicap International <sup>b</sup>	NGO

Abbreviations: FOU, foundation; GOV, government-affiliated association; NGO, non-governmental organisation; OTH, other type of organization.

<sup>a</sup>Key supporting organisation: Motivation Charitable Trust, UK.

<sup>b</sup>Key supporting organisation: Other organisation and/or people.

<sup>c</sup>Key supporting organisation: RG Active Rehabilitation, Sweden.



**Figure 1** Funding sources for the 22 organisations from 21 countries in percent (total 100%).

6 from Asia and 5 from Africa. Table 1 presents the profile characteristics of the participating organisations, which are listed based on the alphabetical order of the name of their country.

**The profile of the organisations that use components of the AR approach**

The majority of participating organisations ( $n = 17$ ) had status of non-governmental organisations (NGOs), two were registered as

foundations, one as government-affiliated association and two had other statuses. Based on data analysis and historical information, RG Active Rehabilitation from Sweden, and Motivation Charitable Trust from the United Kingdom were recognised as *key organisations* for supporting organisations from other countries to develop the AR approach. RG Active Rehabilitation supported the introduction and development of AR in five of the participating countries, Motivation Charitable Trust supported AR activities in eight of the participating

**Table 2 Characteristics of AR camp for adults organised within past 10 years in relation to country income**

Characteristics of a typical AR camp for adults	Country income			
	Low	Lower Mid	Upper Mid	High
No. of participants (mean ± s.d.)	21.3 ± 19.3	15.8 ± 5.8	25.8 ± 18.6	16.8 ± 8.7
% of participants with SCI (mean ± s.d.)	87.5 ± 15.0	86.7 ± 19.6	74.0 ± 26.0	85.0 ± 10.0
No. of peer mentors (mean ± s.d.)	3.3 ± 1.0	4.2 ± 3.5	6.2 ± 4.4	7.8 ± 4.0
No. of non-disabled assistants (mean ± s.d.)	3.8 ± 1.5	7.2 ± 4.6	10.0 ± 4.7	9.3 ± 4.2
Ratio of participants-to-peer mentors	6.3:1	5.1:1	4.5:1	1.9:1
Ratio of participants to non-disabled assistants	6.6:1	4.0:1	3.1:1	1.5:1

Abbreviations: AR, active rehabilitation; SCI, spinal cord injury.

countries and the remaining seven countries were influenced by other organisations and individuals (Table 1).

In regard to the funding of the organisations, in two countries (Kenya, Vietnam) organisations were reported to be fully financed by non-governmental foundations. The government covered 85% of the funding of Foundation for Active Rehabilitation (FAR) in Poland and 100% of the organisation in Malaysia. Sponsorship was reported as the main funding source for Alli Opsi, Greece (95% of costs). In all other countries, AR organisations were financially supported by a mix of different sources such as government funding, non-governmental foundations, participant contributions, sponsorship, membership and other sources (Figure 1).

Among participating organisations, FAR in Poland was reported to have the highest number of paid employees ( $n=115$ ) working with AR activities. Five organisations had between 1 and 5 paid employees, whereas four organisations (Ukraine, Bangladesh, South Africa and Greece) relied solely on volunteers.

Financial issues pertaining to fees for participating in the AR training camps were the most diversified elements of AR approach among the countries. More specifically, 70% of the fees at Back Up camps in the United Kingdom, 80% at Alli Opsi in Greece and 100% of the fees in India were paid out of pocket by the participants. In most low-income (LI) and lower-mid-income (LMI) countries, the participation fee was waived as the programmes were supported by institutional donors, NGOs, trusts and foundations. Government funding covered most of the participation fees in Belarus (80%) and Poland (90%), and the full amount in Malaysia and Ukraine.

### Overview of AR activities

Overall, there were small discrepancies between the organisations in regard to offering first contact activities, training camps, follow-up activities and community awareness and educational activities. Motivation Charitable Trust in the United Kingdom did not directly provide any first contact activities or camps for participants, and only focused on training the trainers and supporting other organisations internationally. All other high-income (HI) and upper mid-income (UMI) countries (except from Alli Opsi in Greece) provided *first contact activities* in acute hospitals, primarily on a one-to-one basis and secondarily through group presentations. Less than half of LI and LMI countries (4 out of 11) provided first contact activities in acute hospitals. The vast majority of organisations across all income levels offered such activities in rehabilitation centres.

Within the past 10 years, the number of AR training camps varied greatly between countries, from two in Kenya to almost 200 in Poland. The most common methods to follow-up participants were face-to-face meetings and over the phone. The vast majority of the organisations also offered *activities directed to the general public*, such as

community activities to raise awareness on disability (17 countries), courses to health care and other professionals (16 countries), courses to university students (13 countries) and visits to schools (13 countries). Interestingly, LI countries tended to use primarily the latter as opposed to the other type of activities.

### The use of the 10 key elements in the AR training camps

Despite country region (Europe, Asia, Africa), country income (HI, UMI, LMI, LI), and main supporting organisation (RG Active Rehabilitation, Motivation Charitable Trust), the AR approach was found to be very similar among the 22 organisations from the 21 countries. All 22 organisations utilised and based their activities on designated peer mentors (element 1) who underwent regular training (element 9). The single most commonly reported goal of the participants across all countries, independently to the level of country income, was to 'improve ADL', followed by 'improve wheelchair skills' and 'receive information about life with SCI'. All organisations reported that the design of their AR training camps offered many opportunities to train and advance performance in ADL, wheelchair skills and knowledge on self-management topics (elements 3 and 5).

Small differences among the countries were seen with regard to several issues. In all but one country non-disabled assistants participate in AR camps (element 2). Similarly, sports and recreational activities during AR camps (element 4), as well as eligibility criteria for camp participants (element 7), were found well established in almost all countries. The other remaining key elements of the AR approach were present in the vast majority if not all of the countries. The average duration of a single AR camp varied (element 10). The higher the country income, the longer the camp duration: LI=5.5 days, LMI=6.1 days, UMI=6.8 days and HI=7.8 days.

Seven organisations offered camps for children and adolescents that most of them lasted between 5 and 7 days. Typically, these camps involved less participants and a smaller proportion of persons with SCI compared with adult camps. Furthermore, they had a much higher ratio of assistants to participants as compared with the adult camps.

### The characteristics of the participants and the personnel involved in the AR training camps

Although the main structure of AR camps was found to be the same in all countries and people with SCI were found to be the main beneficiaries of such camps (85% or more), the number of participants and personnel involved in these activities varied among the countries with different income level (Table 2). The mean number of participants during a typical AR camp for adults varied to large extent, from 17 in HI countries to 26 in UMI countries. The higher the income category, the larger the number of peer mentors

and non-disabled assistants. Also, the higher the income category, the lower the participants-to-peer mentor and participants-to-assistant ratios. In LI and LMI countries, most non-disabled assistants were reported to be family members and personal assistants, whereas in most HI and UMI countries they were mostly health professionals or students.

Most countries provided an allowance for their peer mentors, which varied between €0.5 and 80 per day depending on the country. Seven countries used peer mentors purely on a voluntary basis and covered their participation fee of the training camps.

## DISCUSSION

The current study aimed to describe how components of AR approach have been used during the past 10 years around the world. Despite AR approach being established 40 years ago and used in more than 20 countries, this is the first comprehensive description of the approach in the international scientific literature.

In most countries, the approach was used by NGOs with multiple collaborating links between them. Further analysis showed that RG Active Rehabilitation from Sweden and Motivation Charitable Trust from the United Kingdom had a key role with facilitating the development of the approach in other countries. FAR in Poland was the largest organisation in regard to the number of paid employees dedicated to the AR activities and number of training camps. While most of the organisations used volunteers together with paid workers, the exclusive reliance on volunteers is known to have negative long-term implications on the sustainability and further development of such organisations.<sup>19,20</sup>

Despite the country, country region (Europe, Asia, Africa), country GDP and key supporting organisation (RG Active Rehabilitation and Motivation Charitable Trust), the 10 key elements of the training camps were present in nearly all countries. This is a strong indication that while the approach has been adapted to the particularities of different countries with diverse levels of income and specialisation of SCI care, the core characteristics of the approach were clearly present. As with other community peer-based programmes, AR programmes offer a unique learning environment and respond to important unmet needs and unrealised potential.<sup>21</sup> Most importantly, AR programmes respond to the universal need and established right of people with disability for peer support as a measure to promote independence, community integration and well being.<sup>22</sup>

The few observed differences between the organisations were associated either with the country GDP or the key organisation that supported the development of the program. Funding sources for the organisations and for participating in the training camps, as well as remuneration of peer mentors varied greatly between the organisations. Furthermore, a clear trend was observed in regard to the participant/peer mentor and support group ratio, with organisation in countries with low GDP having higher ratio as compared with organisations in countries with higher GDP.

An accurate description of the approach is important for evaluating the effectiveness and for achieving higher level of integration in the health-care system.<sup>23</sup> Higher integration could involve joint goals and responsibilities, close partnership, high degrees of mutual trust and respect, joint arrangements for streamlining processes including referrals, funding allocation and joint arrangements encompassing strategic and operational issues.<sup>24</sup> Available evidence from integrating health- and social care services<sup>25</sup> suggests that higher integration could improve efficiency of processes and services, could create new opportunities for collaboration, offer packages of services for people

with complex needs and increase viability, sustainability and the number of supported individuals.

## AR as compared with other approaches and community programmes

Similarly with other community peer-based programmes,<sup>21</sup> the specific interplay of the learning resources (i.e. participants with SCI, peer mentors, support group and the curriculum) at the AR camps creates a unique learning environment. This is different compared with other interventions that use aspects of peer support such as therapeutic recreation,<sup>26</sup> leisure activity programmes,<sup>27</sup> wheelchair sports,<sup>28</sup> support groups,<sup>29</sup> non-face-to-face<sup>30</sup> or one-to-one peer mentoring programmes,<sup>31</sup> or transitional programmes that involve peer mentors.<sup>32</sup> AR training camps provide group-based training opportunities that offer both intentional and incidental peer support between peer mentors and participants, and among participants.

AR has many similarities with the community-based rehabilitation (CBR), the Independent Living (IL) movement and the task-shifting (TS) frameworks. CBR was initiated by WHO in the 1980s as a way to enhance access to rehabilitation in resource-constrained settings, and later evolved as a multifactorial approach that focuses on equalisation of opportunities and social inclusion of people with disabilities.<sup>33</sup> Movement for IL emerged in the United States in the 1970s and was inspired by disability rights movement. It uses self-help and peer support as key principles.<sup>34</sup> TS approach was introduced by WHO as a way to tackle shortage of experienced health-care providers in prevention, treatment, care and support of HIV/AIDS.<sup>20</sup> It involves the delegation of well-defined tasks from highly qualified health workers to health workers with shorter training and fewer qualifications. As suggested previously,<sup>35</sup> these approaches emerged out of criticism of the traditional rehabilitation model with its dependence on highly trained professionals. While this may be true for AR to some extent, the real generating power for this approach was the unmet needs that people with SCI experienced after transitioning from in-patient care to community.

Lysack and Kaufert<sup>35</sup> discussed that in CBR the curriculum is formed collaboratively by peer mentors, consumers and health professionals, whereas in the IL the control is seen as essentially being with disabled consumers. TS is by design a partnership between health professionals and community workers, some of whom are peer workers, in accordance with clear and predetermined responsibilities. Similarly, AR is a consumer-centred and consumer-driven approach where the curriculum is informed by consumer needs and priorities. It is designed and implemented collaboratively by peer mentors, health professionals and trained community workers.

Similar to CBR, IL and TS, AR has an important role to play in countries of all income levels. In LI and LMI countries, it is primarily the lack of rehabilitation and the inability of the governments to provide rehabilitation services because of limited funding and availability of expertise. As a result, most of the individuals with SCI do not receive any rehabilitation services during their lifetime. In HI and UMI countries, it is the fact that existing statutory rehabilitation does not fully address all the long-term needs of the persons with SCI that would allow them to reach the expected high activity and participation outcomes.

## Implications and future directions

Although the AR approach has been widely used internationally, it has received little to no attention in the literature. Divanoglou and

Georgiou<sup>21</sup> speculated that this paucity of research may be attributed to lack of funding, lack of research expertise or allocation of the limited resources to other priority areas. With a description of the approach in place and a comprehensive and widely accepted description of its key elements, it is now more feasible to conduct studies that evaluate the effectiveness of the approach. More specifically, there is a high need for quality studies assessing the effectiveness, cost efficiency and the perceived benefits of AR approach. A better understanding of the international commonalities and variations of the approach can potentially promote international collaboration on both operational and research aspects. While all the 10 key elements are used by most of the organisations, it would be beneficial to relate them to the international literature.

At an operational level, organisations that use the approach now have access to a clear and scientifically sound description of their method that they could potentially use when advocating for higher integration in the health-care system and funding. While these 10 key elements are widely accepted by the organisations, further steps to standardise the AR approach could strengthen the approach and facilitate its implementation in other countries.

## CONCLUSIONS

Twenty-two organisations from 21 countries used most of the 10 key elements of the AR training camps. This indicates that the main concept of this community peer-based approach for persons with SCI is well established, despite small variations related to country regions, country income levels and key supporting organisation. The interplay of these elements makes this consumer-centred and consumer-driven approach distinctly different from other forms of peer support. AR training camps provide intensive, goal-oriented, intentional, group-based still customised training and peer-support opportunities for individuals with SCI. Given the ageing of SCI population and the improvements in acute management and survival, this type of interventions are likely to have an even bigger role in the long-term management of SCIs.

## DATA ARCHIVING

There were no data to deposit.

## CONFLICT OF INTEREST

The authors declare no conflict of interest.

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